Synopsis

Ph.D in Human Development

Parent's Knowledge, Attitudes and Practice on Pre-requisite Skills for Children with Autism and its Influence on Parents Mental Health and Self-efficacy - A Sensitization Study

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Introduction

In the 1940s, Kanner and Asperger introduced the term "AUTISM." According to the Centers for Disease Control and Prevention (2020), Autism Spectrum Disorder (ASD) is a developmental disability resulting from differences in brain function and connectivity. ASD typically emerges before 18 months of age and persists throughout an individual's life. As they progress through various life stages, their needs for support and accommodations may evolve accordingly. Autism Spectrum Disorder (ASD) is characterized by difficulties in social interaction and communication, avoids eye contact, not interested in peers, does not show facial expressions, echolalia, along with restricted, repetitive behavior. While autistic children share common characteristics, their manifestations vary, making each child unique. This variability adds to the complexity and challenges faced by parents. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) highlights that ASD traits are not consistent at all times, which can contribute to difficulties in daily life.

A systematic review by Arora et al. (2018) across four Indian states, involving 130,599 children, found that 1 in 100 children under the age of 15 have autism. The CDC reported in 2021 that 1 in 54 children were diagnosed with ASD, while reports from 2023 and 2024 indicated an increase to 1 in 36 children. Mahapatra et al. (2019) noted that determining the prevalence of ASD in India remains a challenge due to a lack of awareness and understanding among the general population. Limited resources, a shortage of trained professionals, and cultural and language barriers further hinder the screening and diagnosis process.

Theoretical Approaches to Parent Education for Autism Spectrum Disorders

Parent education for Autism Spectrum Disorders (ASD) incorporates various theoretical approaches. Applied Behavior Analysis (ABA) reinforces positive behaviors to improve communication and social skills, though its adoption is limited by service availability. The Developmental Social-Pragmatic (DSP) model fosters natural communication by following the child's interests, though more research is needed on its effectiveness. Cognitive Behavioral Therapy (CBT) helps parents manage behavioral challenges and improve family dynamics, showing moderate effectiveness in reducing

difficulties. Ecological Systems Theory views autism within a broader social context, emphasizing the role of family, schools, and communities in supporting children with ASD.

Pre- requisites Skills

Pre-requisite Skills are a set of skills that are acquired before moving to learn more advanced skills. For example, a child with autism must acquire skills such as eye contact, response by name, and basic communication before moving on to next level of social interactions and life skills. These early skills serve as a foundation for learning and mastering higher-level abilities, playing a crucial role in the development of children with Autism Spectrum Disorder (ASD). According to Draydale et al. (2015), essential dimensions of pre-requisite skills include scheduling, attention, self-control, self-advocacy, socialization, communication, imitation, and safety. These skills are fundamental for children with autism as they help establish daily routines, regulate emotions, make decisions, and interact with peers and family members. Additionally, imitation skills are vital for learning and adapting behaviors, while safety awareness is necessary to ensure well-being both at home and in external environments

According to Montes and Cianca, (2014) Parents play an indispensable role in supporting children with autism by providing love, guidance, and assistance in overcoming daily challenges. However, care giving can be physically, emotionally, and mentally exhausting. Many parents prioritize their child's needs over their own, often neglecting self-care, social interactions, and personal well-being. Over time, the stress and exhaustion may lead to burnout, negatively affecting both their health and their ability to provide optimal care for their child. When parents focus on their well-being, they are better equipped to handle challenges, creating a stable and nurturing environment that benefits both them and their child.

Raising a child with autism also introduces additional stressors, including family adjustments, financial burdens, lack of social support, and difficulties in time management (Wang et al., 2020). These factors can significantly impact the mental and physical health of parents, ultimately affecting their parenting efficacy. Many parents experience feelings of guilt, believing they are not doing enough for their child, which can result in emotional and physical exhaustion. This struggle often makes it challenging to maintain a balance between care giving responsibilities and self-care.

Despite the overwhelming challenges parents face, most studies prioritize training for autistic children and educators while neglecting parental needs. However, parents also require

training on how to effectively raise their child while maintaining their own well-being. Addressing parental challenges through support programs, training sessions, and mental health resources is essential in ensuring that they can provide the best possible care for their child while safeguarding their own health.

Research Gap

- Mostly studies are focusing on intervening children but not parents. As a result, the existing evidence on this topic is limited.
- Research on children with autism focused on training children to learn self help skills or functional skills not pre requite skills.
- If parents were involved it was mostly on care giving strategies for the child. Hence, studies were found to be limited on Pre-requisite skills and parent's KAP on pre-requisite skills
- Additionally, there hasn't been enough investigation into how parents can be sensitized to effectively teach essential pre-requisite skills to their children at home

Scope of the study

Children with autism often face significant challenges in social interactions, daily activities, and the ability to generalize learned skills across different settings. These difficulties make it essential for them to receive consistent support from parents and caregivers in routine tasks. However, many parents struggle to provide adequate support due to constraints such as limited time, high levels of stress, and a lack of knowledge about effective teaching methods tailored for autistic children. Without proper guidance, parents may find it difficult to equip their child with the necessary skills to function independently in various aspects of life.

Parental training plays a crucial role in addressing these challenges. When parents receive structured training on how to develop pre requisite skills in their children, they can actively support their child's independence at home, in school, and in their communities. Teaching parents evidence-based strategies for skill-building not only enhances the child's ability to perform daily tasks but also fosters self-sufficiency, reducing dependence on caregivers. Over time, improving these skills can lead to a decrease in problem behaviors, make daily life more manageable for families, and open up greater employment opportunities for autistic individuals. This, in turn, allows them to lead more independent, fulfilling lives with better social and economic integration.

Need of the Study

Parents of children with autism often experience intense emotions such as guilt, anxiety, and sadness when they feel unable to care for their child as they wish. In addition to these emotional struggles, they also face social stigma, which can further diminish their confidence in their parenting abilities. Negative emotions, coupled with a lack of knowledge about pre-requisite skills, can lead to increased dependency on others for their child's daily living activities, making their care giving journey even more challenging. Sensitization programs play a vital role in addressing these issues by helping parents feel understood, reducing societal stigma, and providing the emotional resilience needed to care for their child with confidence. These programs empower parents with knowledge, enabling them to practice essential pre-requisite skills at home, which is crucial for their child's successful development and independence. When parents actively engage in fostering these skills, they support their child's ability to function more independently, paving the way for a smoother transition into adulthood and improving their overall quality of life.

Objectives of the study

Primary objective-

- To explore the Knowledge, Attitude, and Practices (KAP) of parents on Pre-requisite skills of children with ASD
- To assess the levels of Mental Health and Self-efficacy of parents of children with ASD
- To conduct the sensitization programme for parents on pre-requisite skills, positive mental health and self-efficacy and assess its effectiveness.

Secondary objective-

- To examine the influence of Knowledge, Attitude and Practice (KAP) of parents on pre-requisite skills on their Mental Health (MH) and Self Efficacy (SE)
- To explore the socio demographic factors of parents and its influence on their Knowledge, Attitude, and Practice (KAP), Mental Health (MH) and Self Efficacy (SE)

Hypotheses of the study-

- H_{01} - Parents of autistic children have lower levels of Knowledge, unfavorable Attitudes, and lower Practices on Pre-requisite skills
- H_{02} Parents of autistic children have poor mental health status

- H_{03} Parents of autistic children have lower self-efficacy
- H_{04} Parents' knowledge, attitudes, and practices do not influence mental health and self-efficacy
- H_{05} Mental health status of parents does not influence KAP and Self-efficacy
- H_{06} Socio-demographic markers do not determine parents' Knowledge, Attitudes, and Practices on Pre-requisite skills, mental health, and self-efficacy
- $H0_{7}$ Sensitizing parents can improve their KAP on pre-requisite skills, mental health and self-efficacy

Conceptual frame Work

- Raising a child with Autism Spectrum Disorder (ASD) presents numerous challenges for parents. Many autistic children struggle with responding to their names, making eye contact, and engaging in social interactions and communication. These difficulties can significantly impact their daily lives, making routine tasks more complex. Consequently, parents often experience physical, emotional, financial, and mental strain, leading to exhaustion, anxiety, and stress. Their concerns about their child's future further add to their burden.
- One way to support both autistic children and their parents is by introducing prerequisite skills, which include essential abilities such as scheduling, attention, communication, imitation, socialization, self-control, safety awareness, and self-advocacy. Parents need to be aware of these skills as they play a crucial role in a child's development and independence.
- To understand whether parents have knowledge of these skills, we aim to assess their Knowledge, Attitudes, and Practices (KAP) regarding prerequisite skills. Additionally, we will examine how socio-demographic factors such as gender, occupation, education, family type, income, and area of residence influence parents' KAP, mental health (MH), and socio-emotional well-being (SE). Identifying these influences will help us tailor effective interventions.
- Based on our findings, we have designed a sensitization program to improve parents' mental health, socio-emotional well-being, and KAP on prerequisite skills. This program will provide training and awareness sessions on key topics related to prerequisite skills and mental health, equipping parents with the knowledge and tools to better support both their child's development and their own well-being.

- The expected outcome of this initiative is an enhanced understanding of prerequisite skills, improved mental health, and stronger socio-emotional well-being among parents of autistic children.

Methodology

Taking into account the theoretical framework, literature, and studies discussed in the previous chapter, the methodology for the study is outlined in the following sections. Based on the objectives and the analysis of findings from the reviewed literature, the researcher has developed the following research questions.

Research Questions

1. Do parents of autistic children know, believe and practice the pre-requisite skills of children with autism?
2. Does parents' KAP on pre-requisite skills influence their mental health and self-efficacy?
3. Do socio-demographic factors determine parents' KAP, mental health and self-efficacy?
4. Does sensitizing parents improve their KAP on pre-requisite skills, mental health, and self-efficacy?

Following the research questions, the methodology of the study was planned in four phases

Phase 1

- **Literature survey-** Review of Literature has been collected based for both national and global studies.
- **Population and sampling-** The study was conducted in Coimbatore, Tamil Nadu with 143 parents of children with autism. The study followed action-based cross sectional design by adopting purposive sampling technique. A total number of 16 special schools were shortlisted for the present study. However, only 5 schools accepted to be a part of the research.
- **Seeking permission from special schools**- The consent letter was submitted to the school authorities and their permission was sought to conduct the study in their respective schools.
- **Obtaining Ethical clearance**- The study was also approved by the Institutional Human Ethics Committee of the University (approval No. IHEC/19-20/HD/46).

Phase 2

- **Rapport building and consent-** Established a rapport by talking to the parents about the needs and objectives of the study. Consent was taken and the assessment scale was given to parents, and was assured of the confidentiality of the data. Present study included Parents of children enrolled in special schools and excluded parents of children with co morbidities and other disabilities
- **Tool development-** Four tools were used-
  - **Socio demographic**- Self developed tool to elicit socio demographic profile of Parents of Children with Autism which includes gender of parents, Qualification, Occupation, Family income, No. of Siblings, Types of family and Area of residence.
  - **Self-developed tool to assess the levels of KAP-** A Likert scale consisting of 35 items was developed by the researcher to assess the Knowledge, Attitude and Practices (KAP) of parents towards pre-requisite skills. The items covered the aspects of scheduling, attention, socialization, self-control, self-advocacy and safety, communication, imitation. In the knowledge scale, each item had 3 responses indicating yes, no, don't know with 0, 1, and 2 ratings. In the attitude scale each item had 5 responses indicating strongly agree, agree, neither agree nor disagree, disagree, strongly disagree with 1,2,3,4 and 5 ratings and vice versa for negative item and in the practices scale each item had 3 responses indicating always, sometimes and never with 1,2, and 3 ratings. The KAP scale that was constructed by the investigator were submitted to five subject experts from the disciplines of Human Development, Special education, Clinical psychology for their valuable suggestions and inputs in the content of the scale. The feedback and suggestions from subject experts were considered and incorporated by the investigator for the final scale. The reliability was tested using Cronbach's alpha reliability test, score of 0.94 for knowledge, 0.84 for attitude and 0.79 for practice showed an excellent, very good and good reliability of the scales. Validity was tested using principle component analysis (PCA) were the sampling adequacy was also found to be adequate for KAP with 0.760, 0.846 and 0.645 respectively and Bartlett' test of Sphericity showed the significant level with cumulative percentage of 69.240 for knowledge, 69.652 for attitude and 69.201 for practices which were in the acceptable ranges.
  - **Mental Health Inventory (MHI) Jagdish and Srivastava 2005**-Additionally, to appraise the level of mental health the Mental Health Inventory was used, developed by Jagadish and Srivatsa in 2005, comprising 54 items rated on a 5-point Likert

scale. These items were grouped into six dimensions, namely Positive Mental Health Self-Evaluation (PMHSE), Perception of Reality, Integration of Personality, Autonomy, Group-Oriented Attitudes, and Environmental Mastery, with response options ranging from 'very good' to 'very poor.' The total scores were indicative of the level of mental well-being among the parents, with higher scores representing better mental health and lower scores indicating poorer mental health status.

- **Early Intervention Parents Self-Efficacy Scale (EIPSES) Guimond, Wilcox, & Lamorey,2008-** The collection of data regarding parental self-efficacy the Early Intervention Parenting Self-Efficacy Scale was used (EIPSES), developed by Guimond, Wilcox, and Lamorey in 2008. This scale comprised 16 items, employing a 7-point Likert-type scale that ranged from 'strongly disagree' (1) to 'strongly agree' (7). The scoring range for parental self-efficacy varied from high to low, with higher scores indicating a greater of self-efficacy and lower scores indicating low self efficacy.

- **Data collection**

Phase 3

- **Development of an educational module (Sensitization Programme)-** After the completion of first phase of data for 143 parents, the data was analyzed with descriptive statistics using frequency and percentages to know the levels of KAP. In the second phase the respondents were divided into control and experimental groups for the sensitization programme. Based on the consent given by parents to participate in the sensitization programme, a total of 30 parents were taken as the experimental group and 30 parents were taken as control group. The investigator conducted the sensitization program over a period of 15 days, six days per week (Monday to Saturday) with a duration of one n half per session. The sensitization sessions were conducted in Coimbatore. The objective of the sensitization program was to enhance the KAP, MH and SE of parents on pre- requisite skills. The sensitization modules were developed based on a model of instructional design called the ASSURE model by Forest (2015)
- **Conduct Sensitization Programme-** Based on the ASSURE model investigator developed 12 sessions to sensitize parents on KAP. All sessions were planned including basic knowledge on autism, and dimensions of KAP on pre-requisite skills like scheduling, imitation, attention, socialization, self control, self-advocacy, and

safety along with positive mental health and self efficacy. The resource persons from the field of human development, special education, and clinical psychology were identified to sensitize parents on pre-requisite skills. The sensitization programmme was conducted effectively using audio-visual aids. Focus group discussions were held after every session where the issues brought up by parents were discussed. Parents came up with issues they faced such as how to talk with a child, how to teach hygiene, finding the right schedule and healthy lifestyle, the need to train children to distinguish between family members, friends, and strangers, etc.

Phase 4

- **Post sensitization data collection-** On the last day of the sensitization programme post-sensitization data was collected from the experimental group as well as control group respectively. After a gap of 10 days and a gap of one month from the last day of the sensitization program follow-up one and follow-up two data were collected from the experimental group of parents.

- **Pre and post data analysis-** A statistical test such as paired sample t-test was done to find the significant differences between the pre and post KAP scores of control and experimental group. Cohen'sd was calculated to check the effect size. MANOVA analysis was used to see the effect and variance between the post-sensitization, follow-up one, and follow two data and to check the sustainability of the sensitization programme.

Results and Discussion

(i) Demographic profile

The study found that 75.5% of respondents were mothers, reflecting their primary care giving role. Educationally, 58% were postgraduates, 38.5% graduates, while a small percentage had completed higher secondary (2.1%) or a Ph.D. (1.4%).Autism significantly impacts family life and income. 64.3% of mothers were homemakers, while 21.7% of parents worked in the private sector. Financially, 71.3% had an annual income of ₹ 5-10 lakhs, 20.3% earned ₹ 2-5 lakhs, and 8.4% earned above ₹ 10 lakhs. Most families (81.8%) had a single child. The majority (75.5%) lived in nuclear families. Urban residents comprised 85.3%, while 14.7% lived in rural areas.

(ii) **Parent's level of Knowledge, Attitude, Practices, Mental Health and Self efficacy of children with autism**

The study found that most parents had average to low knowledge of pre-requisite skills. Majority of them were showing unfavorable attitudes toward these skills and average to low level of practices. Additionally, parents exhibited poor to very poor mental health along with low self-efficacy.

(iii) Predictive Capacity of Socio demographic factors on KAP, MH, SE

- Multiple liner regression was use to identify the predictive capacities of socio-demographic factors, KAP ,MH and SE .
- The study revealed that few socio demographic factors significantly influenced parents' knowledge, practices, and mental health, though they did not strongly predict attitude and self-efficacy.
- Within the knowledge domain, the perception of reality, how parents understand and interpret their child's needs was a key predictor of mental health, suggesting that a clearer understanding of their child's condition contributes to better well-being.
- Additionally, participation in group-oriented activities was found to enhance self-efficacy, indicating that collaborative learning and community engagement help parents feel more confident in their care giving abilities.
- In terms of attitude, the attention given to pre-requisite skills influenced mental health, meaning that parents who actively recognize their importance tend to experience better psychological well-being, although this did not directly impact their self-efficacy.
- Regarding practices, overall engagement in pre-requisite skill-building activities was linked to improved mental health, while the ability to express emotions was a significant predictor of self-efficacy, highlighting the role of emotional responsiveness in fostering parental confidence.

(iv) **Predictive Capacity of KAP on MH and SE**

- Within the domain of knowledge, specific dimensions were found to be significant predictors of mental health and self-efficacy. The self-control dimension of knowledge demonstrated a significant predictive relationship with mental health, accounting for 6.3% of the variance. This finding suggests that individuals with

greater self-control in their knowledge framework may experience better mental well-being.

- Furthermore, the socialization dimension of knowledge emerged as a significant predictor of self-efficacy, explaining 5.8% of the variance**.** This indicates that parents with a stronger understanding of socialization processes are more likely to exhibit higher levels of self-efficacy, potentially improving their ability to manage and support their child's needs effectively.
- Among the various dimensions of attitude, the attention dimension was found to be a significant predictor of mental health, accounting for 8.3% of the variance. This finding highlights the role of attentiveness and mindfulness in shaping mental well-being among parents of autistic children. However, none of the attitude dimensions were found to be significant predictors of self-efficacy, suggesting that while attitude influences mental health, it may not have a direct impact on parents' confidence in their care giving ability.
- The analysis further revealed that overall practices significantly predicted mental health, contributing 9.7% of the variance. This finding suggests that the behavioral practices adopted by parents play a crucial role in their psychological well-being.
- Additionally, the expressing emotions dimension of practices was identified as a significant predictor of self-efficacy, accounting for 16.1% of the variance**.** This indicates that parents who effectively express their emotions are more likely to develop a higher sense of self-efficacy, which may enhance their ability to cope with the challenges associated with raising a child with autism.
- These findings emphasize the importance of different dimensions of knowledge, attitude, and practices in influencing both mental health and self-efficacy. While self-control in knowledge and attention in attitude are key predictors of mental health, socialization in knowledge and emotional expression in practices play crucial roles in enhancing self-efficacy. These insights highlight the need for targeted interventions that focus on improving specific areas within KAP to promote overall well-being among parents of autistic children.

The result shows that raising a child with autism is a unique and independent journey for each parent. While different factors and socio demographic conditions may have influence at times, but the overall parenting experience shapes their beliefs and perspectives in a lasting way. Through their experiences, parents develop attitude and a mindset of care giving approach that remains stable despite external influences.

Their lived experiences shape their knowledge, attitudes, practices, mental health and self-efficacy. Regardless of whether they are affected by external factors or not, parents always prioritize their child's care, follow necessary routines, and adapt to their circumstances to provide the best support possible.

(v) Paired t test and MANOVA

- Present investigation was done to assess the effect of sensitization programme and see the significant difference between KAP, MH and SE among the experimental and controlled group in pre and post sensitization.
- Study reveals that the post-sensitization scores were found to be higher than the pre-scores in the knowledge, attitude, and practices among the experimental group parents, showing significant differences with small and medium effect.
- Differences between Control and Experimental Groups- The analysis revealed no significant differences in Knowledge, Attitude, and Practice (KAP) scores, as well as in Mental health and Self-efficacy, within the control group. This suggests that, in the absence of intervention, there was no measurable change in these variables. However, in the experimental group, a significant improvement was observed between pre-test and post-test mean scores, indicating substantial positive changes following the sensitization program.
- Effect size analysis using Cohen's d showed variation in the magnitude of these improvements. Specifically, Knowledge exhibited a small effect size, while Attitude and Practice demonstrated medium effects. Similarly, mental health displayed a smaller effect, whereas self-efficacy showed a medium effect. These findings suggest that the sensitization program had a notable impact on both behavioral and psychological aspects among parents of autistic children.
- The analysis of mean differences across four assessment points—pre-sensitization, post-sensitization, follow-up 1, and follow-up 2. The Wilks' Lambda value indicated a statistically significant difference in mean scores across these time points, confirming that the intervention had a meaningful impact over time.The assumption of sphericity was tested for different variables. It was assumed for KAP measures but not for mental health and self-efficacy, suggesting that different statistical considerations were required for these factors.
- Univariate analysis revealed a significant interaction between subject factors and Knowledge, with a Partial Eta Squared value indicating that 51% of the variance in

Knowledge. Similarly, Attitude accounted for 50% of the variance, while Practices contributed 47.6%. These findings demonstrate the effectiveness of the sensitization program in improving KAP levels among parents.

- Beyond KAP, the program also had a profound impact on psychological variables. Mental health improvements accounted for 96.6% of the variance, highlighting the substantial influence of the intervention on parental well-being. Additionally, Self-efficacy showed a meaningful change, explaining 33.9% of the variance. These results underscore the importance of structured sensitization programs in fostering both behavioral and psychological growth among parents of autistic children.
- Overall, the findings indicate that the sensitization program was highly effective in enhancing parental knowledge, attitudes, and practices, while also promoting better mental health and self-efficacy. These improvements highlight the need for continued support and intervention programs for parents of autistic children to enhance their overall well-being and care giving abilities.

Conclusion

Parents raising children with autism face multiple challenges, which puts a lot of fretfulness on parents themselves and their families. They might need to spend a lot of time helping their child get the support they need, eventually overlooking their own needs and interests, which can be very stressful and exhausting, as it may be tough to make time for them and family, affecting their relationships and mental well-being. Parents of autistic children reported low levels of knowledge and practice of pre-requisite skills and unfavorable attitudes. They even had poor levels of mental health status and low self-efficacy.

Dimensions of knowledge, such as perception of reality and group-oriented activities, were found to predict mental health and self-efficacy, respectively. The dimension of attention in attitude predicted mental health but did not predict self-efficacy. Overall practices and only expressing emotions predicted mental health and self-efficacy, respectively. A few socio demographic markers have significant predictive capacities only on parents' knowledge, practices, and mental health.

The post-sensitization scores were found to be higher than the pre-scores in KAP among the experimental group parents, showing significant differences with small and medium effect. Similar results were observed in the mental health status and self-efficacy as well. The MANOVA results also showed that differences between the scores of pre- and post-test and of follow-up1 and follow-up2 were significantly different. The score showed a

drastic increase during the post-test, sustained through follow-up one, and follow-up two, indicating the positive effect of the sensitization programme on the KAP levels, MH, and SE of parents of autistic children.

Hence, hand-holding and motivating parents of autistic children through educational sensitization, intervention, and training programmes can bring about a change in the lives of parents and children, leading towards sustainable mental health and well-being

Implications

The implications of the study are under the following heads

1. For parents themselves - to address their mental health concerns, stress, burnout, and work-life balance, to seek professional help
2. For the organizations and professionals working for autistic children – to focus on parents' needs, dealing with financial burdens, start parent support groups to mitigate negative impacts, create support services through educational interventions, support and parental well-being
3. To the policy makers – to consider opening support services to parents for their development and well-being, to improve coping mechanisms, and to provide professional help for the parents of autistic children and also other disabilities.
4. Families – to provide unconditional support for parents, shared responsibilities in bringing up a child with autism

Limitations

- Small sample size is one of the major limitations of the study
- The study is limited by its focus on a specific geographic area, which may restrict the generalizing ability of the findings.

Recommendations

- Study a large sample size with cultural stratification
- To study the parents of children with other disabilities
- Development of interventions specifically designed for parents of autistic children to deal with mental health and well-being

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